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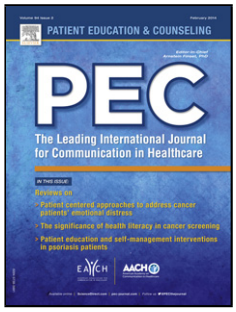

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Potential positive impact of group-based diabetes dialogue meetings on diabetes distress and glucose control in people with type 1 diabetes

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Highlights

- Diabetes Dialogue Meetings (DDMs) potentially reduces diabetes distress and HbA1c
- Peer support was perceived as the main benefit from participation
- The content of the meetings was partly participant driven
- Experienced clinical health care providers facilitated the meetings
- Results from this exploratory pilot-study can help guide a future randomised trial

Abstract

Objective: To evaluate the effect of group-based diabetes dialogue meetings (DDMs) on diabetes distress, perceived competence and glycaemic control.

Methods: Patients with type 1 diabetes (T1D) were invited to DDMs with peers and healthcare professionals. The impact of participation was evaluated by change in diabetes distress measured by Problem Areas in Diabetes (PAID), diabetes competence measured by Perceived Competence in Diabetes (PCD), change in HbA1c before and one year after the DDMs.

Results: 120 patients with T1D participated in at least one DDM: 75% female, mean age 50 years (range 21-76), mean diabetes duration 23 years (range 0-64); 39% of all participants had a baseline PAID score $\geq$ 33, indicating high levels of distress. After one year, both PAID (from 30.4±16.6 to 27.4±17.1; n=81, p=0.03), and mean HbA1c (61.6±10.2 to 58.8±9.9; n= 120, p<0.0001) had improved significantly. PCD showed no change. Meanwhile, the benefit from participating was rated high with a median of four out of five and the major gain being the possibility to share experiences with peers.

Conclusion: Group-based DDMs were highly appreciated by participants and associated with significant improvements in diabetes distress and HbA1c.

Practice implications: DDMs target a large group of patients using few staff resources.

Keywords: Patient education, patient participation, peer support, disease specific distress, Type 1 diabetes, chronic disease

1. Introduction

Learning to live with diabetes is influenced by a number of factors including self-efficacy, sense of coherence, and perception of competence in managing the daily challenges of the disease (1-3). In the past decade, the challenges of living with diabetes have received increasing attention with studies reporting a prevalence of diabetes-related distress as high as 20 to 30 percent among people with type 1 diabetes (T1D) (4-6). In addition, studies have found that the level of engagement in diabetes self-management behaviours is influenced by level of diabetes distress (7), which in turn has been found to be associated with level of HbA1c (8). Promoting self-management through education involving both the physical and psycho-social challenges of diabetes has been shown to have a meaningful contribution to leading a good life with T1D. Support of diabetes self-management behaviours is an on-going process in which new skills must be acquired and applied, and might affect not only biological measures, but also the quality of life and the level of distress (9-11).

Although self-management education has become more available, integrating diabetes management into everyday life remains a significant challenge to many people with diabetes (12, 13). The possibility of sharing the burden of the disease and self-management strategies with peers as an adjunct to usual care has been found to improve well-being and overcome barriers to successful self-management primarily in people with type 2 diabetes (T2D) (13, 14) . While individual consultations with health care professionals (HCPs) might provide knowledge about the self-management of diabetes; peer group interventions are likely to break down feelings of isolation and promote feelings of relatedness and hope (14, 15). However, no specific effective method concerning appropriate length of time or setting for peer support to promote self-management in adults with T1D has been found (13, 14). Likewise the combination of peer support and provision of theoretical knowledge by HCPs has not been investigated in great detail. Based on a previous study on peer support facilitated by experienced HCPs showing significant reductions in diabetes distress and depressive symptoms in adults with T1D (16), we wanted to investigate if the benefits of peer support could be extended to a larger group of people with T1D. As major alterations had been made to the original peer support intervention (16) the study was conducted as an exploratory pilot study to gain sufficient knowledge that might guide the planning of a future randomised controlled test (RCT).

2. Methods

We conducted an exploratory concurrent mixed method pilot study to investigate the perception of participation and the impact of so called group-based Diabetes Dialogue Meetings (DDMs). The purpose of using a mixed methods approach was to provide complimentary knowledge of how specific factors were affected by participation in the DDMs and to explore aspects that affected the participants' perception of their benefit from the meetings. The exploratory design did not require inclusion of a control group and thus a pre-post-test with follow up after one year was chosen to determine the long term impact on diabetes distress, perceived competence in diabetes, and HbA1c. The DDMs were structured meetings facilitated by a multidisciplinary team of HCPs where people with T1D met with peers and ,in addition, received self-management education. Inclusion criteria were having T1D and attending Steno Diabetes Center (SDC), a diabetes center providing a multidisciplinary service for about 3600 adults with T1D and 2200 patients with complicated T2D. People with T1D were recruited to the study in multiple ways in order to explore the interest in participation among a selected, a randomly selected and an unselected sample respectively. Prior to the first DDM a letter of invitation was sent to a selected sample, namely all people with T1D previously attending the aforementioned support groups (n=54), and 100 randomly selected persons with T1D from our hospital database. An open invitation was also available in the outpatient clinic waiting area and on our webpage, two to three months in advance of the DDM. For the subsequent DDMs participants were only recruited through invitations in the outpatient clinic and on the webpage providing all people with T1D at the center a possibility to participate in the meeting. The invitation was specific to each DDM and highlighted gaining knowledge about diabetes self-management and sharing experiences with peers regarding the perceived challenges of diabetes self-management as the objectives of the meeting. Furthermore the invitation provided information on the topic, the programme and the evaluation of the DDM.

The DDMs were inspired by empowerment and social learning theory (13, 17) Four meetings were held between May 2012 and October 2013. The DDMs were facilitated by four experienced and qualified HCPs who had previously facilitated support groups (16): Two diabetes specialist nurses, an endocrinologist and a dietician. The DDMs were held in the evening in a conference room with round tables at our clinic. Each meeting lasted two hours including a break during which coffee, tea and bread rolls were served. Participation was free of charge. The programme of the first three DDMs included an introductory lecture with a specific topic delivered by a HCP followed by an

experience based talk on the same topic by a person with T1D. The purpose of the experience based talk was to give examples of day-to-day use of the self-management strategies discussed in the lecture. The persons with T1D who gave the talk were invited according to their experiential knowledge of the subject as discussed with one of the facilitators during a previous consultation or educational session. Following the talks the participants had the opportunity to discuss the topic and share experiences with others in groups of six to eight people sitting around the same table. At the end of the meeting representatives from each group shared the most important aspects discussed within the group (see Box 1).

The topic for the first meeting, *carbohydrate counting*, was decided by the facilitators based on previous experiences of areas of common interest to people with T1D. The subsequent topics were decided based on suggestions from the participants at the previous meeting. The topics were *exercise; psychological challenges; and fluctuating blood glucose values*, respectively.
In addition to providing suggestions regarding topics for the next meeting; the participants also expressed their preferences regarding the format of the meetings. According to these preferences the format of the fourth DDM with the main topic *fluctuating blood glucose values* differed from the previous meetings. Corresponding to these preferences participants attending this meeting were split into four groups based on their diabetes duration. After a short introduction to the main topic all groups took part in four consecutive workshops each lasting 25 minutes and relating to various aspects of the main topic. The topics were: workshop 1: blood glucose measurements and insulin injection technique; workshop 2: exercise; workshop 3: food; and workshop 4: the emotional impact on fluctuations.
Usual care for people with T1D attending SDC included attending individual appointments with HCPs at the outpatient clinic every three to four months. The focuses of these appointments are self-management education and prevention of complications. As a rule SDC has a strong emphasis on obtaining individual HbA1c levels that are within the recommended target for people with T1D. For the duration of the study no other interventions that included a specific peer support component were offered to people with T1D.
Participant data was evaluated prior to and one year after the participation in one or more DDM(s). The primary end-point was change in diabetes distress, as evaluated by Problem Areas in Diabetes (PAID) (18). PAID consists of 20 items rated on a 5-point scale (0–4) ranging from ‘no problem’ to ‘very serious problem’ and was transformed to a 0–100 scale by multiplying the score with 1.25

(18). Scores ≥ 33 indicate a high level of diabetes-related distress (19). Secondary outcomes were change in HbA1c, and the degree of competence in managing diabetes was evaluated by the Perceived Competence in Diabetes Scale (PCD). PCD consists of five items that are scored from 1 'strongly disagree' to 7 'strongly agree' and summarized to a scale from 5-35(5).
At the end of each DDM the participants also filled in a self-reported outcome evaluation form consisting of five questions about their personal perception of and benefit from the meeting on a five point scale: Question 1: Was your benefit from the introductory lecture satisfactory? Question 2: Did you gain new knowledge from the introductory lecture? Question 3: How would you rate your benefit from the discussion in the small group afterwards? Question 4: Were you satisfied with the format/planning of the DDM? Question 5: How do you rate your overall benefit from participating in the DDM? Questions 1, 2 and 5 ranged from not at all to a large extent, and questions 3 and 5 ranged from very little to very much. In order to engage participants in the planning of future DDMs they were asked to give suggestions regarding topics and format. Lastly, they were asked in an open-ended question to state in one sentence their perceived benefit from participating. These statements revealed participants' views on aspects that they found were important in regards to the intervention. The statements were analysed using inductive thematic analysis. Data were systematically organized into meaningful groups with tentative codes in order to find patterns and meanings pointing to more specific themes in a process that went back and forth (20).

Statistical methods

Non-parametric analysis, Mann-Whitney *U*-tests for groups, Wilcoxon signed-rank tests for paired analyses, and Spearman association analyses were used throughout due to the relatively small sample size and non-normal distribution. All statistics were computed using NCSS statistical software. All tests were performed as two-tailed with significance set at 5%. Continuous data are presented as mean ± standard deviation, and categorical data as percent, unless stated otherwise.
If ≤ 50 % of the items on one of the scales were missing when transforming items into scales, the mean of the remaining items was used to replace the missing values (this was done in 0.3 % of the items). Otherwise the entire scale was regarded as missing. Four scales in total (two of each scale) were not included in the analysis as missing data were disregarded in the paired comparisons.

Ethical considerations

All data was treated as confidential and the entire study was approved by the Danish Data Protection Agency (J.nr. 2012-41-0466).

3. Results

Quantitative evaluation

A total of 120 persons with T1D participating in at least one of four DDMs were evaluated in the present investigation. On average 55 (range 48-62) people with T1D participated in the DDMs. Nineteen participants were recruited by letters of invitation to the 54 previous attendants of support group meetings, nine from the randomly selected group of people with T1D from the hospital database, and the remaining 92 participants through invitations in the outpatient clinic and on the webpage. Baseline characteristics for the subjects are shown in Table 1. The majority of the participants were women (75%), and these were significantly younger than the men (48±13 *vs.* 56±14 years of age, p=0.01). PCD at baseline was slightly higher in men (32±4 *vs.* 29±6, p=0.01), whereas the baseline PAID score was significantly lower in men (22±15 *vs.* 33±18, p=0.002). The PCD and PAID questionnaire response rate at baseline was 93% (n=112). On average, 39% of all participants who answered the questionnaire at baseline had a PAID score ≥ 33, indicating high levels of diabetes distress. An average PCD around 30, on the other hand, indicates a high level of perceived competence. PCD at baseline (r=-0.20, p=0.04), but not PAID (r=0.13, p=0.2), was negatively correlated to baseline HbA1c.

At the one-year follow-up, 81 of the original 112 PCD and PAID questionnaire responders returned the follow-up questionnaire (72% of the original responders, 68% of the baseline cohort). Although non-significant, as might have been expected, these two-time responders were slightly older (52.0±13.4 *vs.* 47.0±13.4 years, p=0.07), and had a longer duration of diabetes (24.3±16.1 *vs.* 19.0±14.1 years, p=0.07). At follow-up there was a significant decrease in PAID (Table 2). In the group of participants who responded to the follow-up questionnaire, the proportion of participants with a PAID score ≥33, decreased from 41 to 37% (p<0.0001). There was no change in PCD (Table 2). HbA1c showed a small but significant decrease of 3±7 mmol/mol; from 62±10 to 59±10 mmol/mol (7.8±3.1 to 7.5 ± 3.1%); (p<0.0001; n=119) by one year (361±59 days). As expected, higher baseline HbA1c was associated with a greater HbA1c decrease (r=0.40, p<0.0001), but there were no differences with respect to age, gender, diabetes duration, PCD or PAID (data not shown).

The one-year HbA1c decrease was similar in the PCD/PAID responder cohort to that of the entire treatment group. There was no difference in the distribution of gender, age, duration of diabetes, HbA1c, PCD or PAID with respect to number of attended DDMs (data not shown). But it was more common among the participants with previous experience of attending a support group at the clinic to also attend at least one DDM than it was among the one hundred randomly invited people with T1D (43 vs. 9 %, $p<0.0001$). Overall the evaluation of the DDM showed that the participants rated their benefit from participating as high with a median score of four out of five.

Qualitative evaluation

The qualitative part of the study investigated what aspects of the intervention the participants perceived to benefit most from through thematic analysis of the open-ended question on the evaluation form.

The possibility of sharing experiences concerning life with T1D with peers was regarded as the most important benefit of the DDMs. Being among peers paved the way for sharing experiential understanding, leading to a feeling of interrelatedness as expressed by this participant:

> *It is always rewarding to meet others who are in the same situation as you. The very fact of being in a larger assembly where the majority of those present are diabetics was a very special feeling. Normally, I am always (almost) the only one who is "different".*

The introductory session by an HCP and a person with T1D with the following dialogue in small groups was regarded as a good combination, although some participants would have appreciated more time in the small groups. Attitudes to and challenges in the management of T1D were discussed. Ideas were exchanged in a manner that encouraged the participants to try new experiments or treatments, exemplified by the following statement:

> *I was even keener to try pump therapy after participating and listening to different statements.*

The recognition from peers that living with T1D takes time and energy was perceived as a relief for the participants. They felt they were no longer alone in struggling with challenges. This dialogue led to the following reflection on managing life with diabetes:

> *It is rewarding to hear how others manage their diabetes. Some have very difficult conditions both privately and at work and still they manage to get by (and they jolly well have to). That gives food for thought even though you do not feel better yourself because others are felling worse.*

In addition, some participants expressed that offering DDMs was perceived as recognition on the part of the diabetes clinic regarding the need for additional support in managing and living with T1D:

> *You [the clinic] are great at being at the forefront of our problems and you are open towards our comments and emotions.*

4. Discussion and Conclusion

4.1. Discussion

We conducted four group-based thematic meetings for people with T1D where the content was partly participant-driven and the dialogue facilitated by experienced HCPs. The one-year pre-post follow-up showed a significant reduction in levels of diabetes distress and HbA1c, but no change in perceived competence in managing diabetes. The DDMs were highly appreciated by the participants. The major perceived benefit of participating was the opportunity to feel recognized as a person challenged by a life with T1D and share these experiences with peers.

Based on a previous study on the benefit of support groups with a limited number of participants showing positive results regarding reduction of diabetes distress the current, still, small size piloting study has demonstrated a positive effect for a larger sample of self-referred people with T1D. The intervention targeted the multidimensional aspects of living with diabetes. Participants were actively involved in designing the format and content of the meetings to increase relevance. Specific self-management behaviours and psycho-social challenges in performing these behaviours were the centre of attention in the DDMs. The novelty of this study is the limited time requirement of interaction between the participants and the HCPs necessary to obtain reductions in diabetes distress and HbA1c. In addition, the intervention was delivered by experienced clinical HCPs in collaboration with people with T1D and could easily be transferred to other clinical settings with little effort if the results are replicated in a RCT.

Our previous study (16) showed intervention benefits were not limited to a sample of people with T1D defined by either level of HbA1c or distress. Therefore inclusion criteria were broad in order to make the intervention available to a large proportion of people with T1D attending our center. The recruitment process was targeted as many potential participants as possible in order explore the interest in and demand of group-based interventions aiming at alleviating the burden of living with diabetes. Although the majority of the participants were women, the group was heterogeneous across age and diabetes duration indicating a need for interventions like this across the life span with diabetes. The relatively low HbA1c in the sample underscored the need for this type of intervention also in people with lower levels of HbA1c as was seen in our previous study (16). The large proportion of participants with a high level of distress likely indicates that the participants were aware of their need for support and therefore availed of the opportunity for psycho-social support when offered. Likewise, the large number of female participants mirrors the well-established significant gender differences in PAID scores (5, 21, 22). Furthermore, the self-referred sample is likely biased towards participants with positive experiences of group-based sessions as opposed to people preferring individual session with HCPs for support.

Views on delivering self-management education that target both HbA1c and diabetes distress vary across interventions. Diabetes self-management education programmes (DSMEs) such as i.e. Dose Adjustment For Normal Eating (DAFNE) focus on delivering education on specific self-management behaviours. Significant reductions in both HbA1c and diabetes distress have been reported from large group-based randomised controlled studies on DSME (23). Similar significant reductions in both outcomes have been found in group-based interventions that combine DSME with attention to psychosocial aspects of living with diabetes (10, 24-26). While the different approaches both reduce diabetes distress and HbA1c one common feature that might positively affect the results is the dynamic of the interactions among peers in the group that cannot be established in individual consultations with HCPs. Although we cannot draw conclusions as to the causality of our findings, group interventions such as ours seem to add a component of social support by providing room for vicarious learning experiences that is likely to relieve the feeling of loneliness and isolation as shown in diabetes (15, 27). The acknowledgement of the burdens around self-management may positively impact self-management behaviours and consequently reduce both distress and HbA1c as reported in other studies (3, 13). Despite the high levels of distress displayed in our sample, the perceived competence in managing diabetes was high at baseline and

consequently did not improve. This has also been observed elsewhere (3). Regardless of a perceived high competence in managing diabetes, a large part of our sample displayed high levels of distress, indicating the need for intervention. While the DDMs were open to all people with T1D attending our clinic, other studies aiming at reducing diabetes distress and HbA1c most often include people with T1D who either have high HbA1c (24, 25) or high levels of depression (26). In our study baseline levels of PAID did not influence the outcome indicating that improvements in diabetes distress are needed across the range of PAID scores. Potentially, DDMs could be offered to people with T1D with high levels of distress and/or high HbA1c as a replacement of one of the annual follow-up meetings at the clinic if a RCT testing the intervention showed significant benefits in improving glycaemic control and psychological outcomes.

Participant involvement is emphasized as a major component in intervention development to ensure relevance and feasibility (28). The participants in our study were invited to give suggestions in relation to topics and structure for the next meeting. In addition, the qualitative data were obtained to explore aspects that participants viewed as important in relation to their benefit from the DDMs. The data reflected participants' appreciation of being listened to and involved in developing ideas. Exploration of participants views regarding the specific useful elements of an intervention could be used in adjusting the intervention and preparing for a future RCT regarding recruitment, content, and outcome measures (28).

A lack of interventions targeting diabetes distress has been identified in the literature (4, 29, 30). Our study suggests DDMs as a way of addressing the multiple dimensions involved in the management of diabetes. Although the intervention significantly decreased diabetes distress the reduction was still small. However, the complementary qualitative data underscored the positive impact of the intervention as experienced by the participants. Nevertheless, sufficiency of the intervention can be questioned by the fact that after one year more than one third of the participants still experienced high levels of diabetes distress. Furthermore, as in our previous study male attendance was low compared to the previously mentioned RCT studies suggesting that this less structured format was not as attractive to men as it was to women (3, 10, 24).

Due to its non-randomized design and limited size, the data should be viewed with caution but encourage further investigation. While we cannot draw conclusions as to the causality of our quantitative results the findings warrant a need for interventions like this targeting the emotional

burden of living with diabetes. However, in order to establish sufficient evidence to conduct a RCT to test the hypothesis that participation in group-based DDMs will significantly reduce diabetes distress and HbA1c in people with T1D more research is needed. Further research regarding enhancements of the intervention to gain larger reductions in the group of participants exhibiting high levels of diabetes distress and HbA1c, increase of uptake among men and the prospect of substituting an annual follow-up visit with a DDM is necessary.

4.2. Conclusion

The results of this study suggest that participation in one or more group-based DDMs with peers and HCPs focusing on the multidimensional aspects of living with diabetes is able to significantly reduce diabetes distress and HbA1c after one year. The DDMs were highly appreciated by people with T1D and the major perceived benefit of participating was the interrelatedness of sharing experiences with peers. However, a more intensive intervention is needed to further reduce the high levels of distress experienced by one third of the participants one year after the intervention.

4.3. Practice Implications

Group-based DDMs seem to be effective in reducing diabetes distress and improving glycaemic control in a sample of people with T1D with elevated levels of distress and HbA1c. The DDMs were facilitated by experienced HCPs and included active participation from people with T1D. The DDMs were held outside of normal office hours, giving the participants an opportunity to meet at a time that was convenient for them. Limited staff resources were required for the intervention.

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Conflict of interest:

Mette Due-Christensen (MD-C), Eva Hommel (EH), and Martin Ridderstråle (MR) are presently employed at Steno Diabetes Center A/S. Steno Diabetes Center is research hospital serving as an integrated part of the public Danish National Health Service and owned by Novo Nordisk A/S. Steno Diabetes Center receives part of its core funding from unrestricted grants from the Novo Nordisk Foundation and Novo Nordisk A/S. MD-C, EH, owns shares in Novo Nordisk. No potential conflicts of interest relevant to this article exist.

M D-C and EH were responsible for the acquisition of the data. M D-C, EH, and MR were responsible for analysis and interpretation of data. M D-C and MR wrote the manuscript. EH critically revised the manuscript. MD-C and EH designed the study. All of the authors approved the final version to be published. M D-C is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Figure

Box 1
Programme outline

10 minutes	Welcome and brief introduction to the topic
25 minutes	Introductory lecture by member of multidisiplinary team
10 minutes	Experience based talk by person with T1D
15 minutes	Break (tea, coffee and bread served)
45 minutes	Dialogue in small groups of 6 to 8 people with T1D
15 minutes	Conclusion of meeting including evaluation

Table 1 Participant characteristics at baseline (median [IQR])

N=120		
Age	(years)	50 (41-62)
Diabetes duration	(years)	20 (9-36)
Gender	Females/Males (n)	90/30
HbA_{1c}	(mmol/mol)	60 (55-68)
	(%-points)	7.6 (7.2-8.4)

Table 2 Baseline and follow-up characteristics for the PAID/PCD follow-up cohort

	Baseline	Follow-up	*p*-value
HbA1c (IFCC mmol/mol)	60 (54-68)	58 (52-66)	0.003
HbA1c (%-points)	7.6 (7.1-8.4)	7.5 (6.9-8.2)	
PAID (median [IQR])	28 (20-41)	28 (14-37)	0.03
PCD (median [IQR])	32 (28-34)	32 (30-34)	0.8
PAID ≥ 33			
HbA1c (IFCC mmol/mol)	63 (56-70)	60 (53-67)	0.004
HbA1c (%-points)	7.9 (7.3-8.6)	7.6 (7.0-8.3)	
PAID (median [IQR])	42 (39-55)	35 (28-51)	0.03
PCD (median [IQR])	28 (27-31)	30 (26-32)	0.6